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Care work and care services under pressure

I am extremely honoured and very, very pleased and happy to have been awarded the prestigious Sohlberg prize. I am especially happy because I interpret the prize as recognition for the research perspectives and topics that I myself and my research group in the Department of Social Work at Stockholm University have been working on for many years (in my case for almost four decades).

We have studied the everyday life of care under different and changing socio-political and organisational conditions, focusing on three female-dominated groups: older people with care needs, their families and paid care workers; those who actually live the consequences of changing public policies. Our research on eldercare in Sweden and in other countries has linked feminist-oriented theoretical perspectives on care to social policy-oriented research on welfare, and to work-life oriented research on the organising of welfare services and the work environment.

I must admit that I started my career as an eldercare researcher quite reluctantly. As many young(ish) persons, I thought it would be boring to study ageing and care of old people. I slipped into the field by coincidence – or rather by being invited by Rosmari Eliasson Lappalainen who, at the time (1985), was working in the R&D unit of Stockholm city. (Later Rosmari became professor in social work at Lund University and a very important person in Swedish care research.) She asked whether I would join her as a research assistant in a study of home care – at that time there were hardly any studies of that field. It was an unknown and ignored part of the welfare state.

First, I said no – I hoped that I would have a chance to do research on younger people instead, maybe on youth unemployment. But Rosmari suggested that I could compare home care work as a low paid occupation for women to another low paid job for women that I had personal experience of: I had been working for seven years as an industrial worker in an

electronics factory. That perspective sounded immediately more interesting to me so I agreed to start working on a home care project in 1985.

As a starting point I was sent out in the field for a pilot study where I followed some home care workers for a couple of weeks. I wrote a short report based on my experience, and the report was included in an application for funding for a larger project. I don't have access to the application, but I re-read my report recently and I noted that it ended with the following words: "What obstacles and opportunities are there to develop public care services for older people that are satisfactory both for those who provide care and for those who receive care?"

In many ways this is a question I have been struggling with ever since. It may sound like a lack of imagination, but I think it is reasonable to argue that the organisational conditions for the eldercare sector have changed so rapidly and drastically that it is relevant to keep asking the original question: under what conditions can care work be organised so that care workers as well as the old and frail people who use their services and their families can have a good life?

The application got funding the year after, and in 1987 and 1988 I conducted a larger ethnographic study of home care that eventually led to my PhD thesis after a few more years that I would like to admit.

In the project, I followed five groups of home care workers in the city of Stockholm for 5-6 weeks each. Besides participant observations I interviewed care workers and their managers as well as care recipients, and later I also analysed the history of home care and the various organisational reforms that had taken place over the years.

My thesis was published in 1995, with the title "The organisation of everyday life: on home helpers and elderly people in Sweden" (Vardagens organisering, in Swedish). I never fulfilled the original plan to compare factory work to care work – I got so fascinated by the world of care I encountered that I totally forgot my factory experience. And soon I realised that it wasn't at all boring to study care for older people and I became increasingly more and more interested in the experiences of the older persons receiving care. I also realised that to understand a relational phenomenon such as care, it is crucial to see to both parties'

perspectives. (I had no focus on informal carers at that time, but it came later and now I would say that there are three parties' perspective that has to be understood.)

I also realised that to make sense of the workers' and the care recipients' experiences, we also have to understand what actually happens in their daily encounters and to relate this everyday practice to the socio-political, organisational and cultural conditions under which the encounters take place.

One of the central findings of my thesis was that, under certain preconditions, it was possible for the elderly home care recipients to receive care that was very satisfying, and tailored to their personal and changing situations.

A key precondition for such individually and situationally adapted care is that the care worker has adequate *knowledge of the situation of the older person*. This requires sufficient *time, continuity* in the relationship and a limited number of care recipients to relate to. In addition, there is the requirement that both the care worker and the old person have a sufficient *freedom of action* in their daily encounters. When the care worker enters the home, she must have autonomy enough to evaluate the actual situation and act accordingly – care work cannot be pre-regulated in details and the tasks to be carried out cannot be pre-defined. Further, it is also important to have *support* from colleagues, supervisors and managers in handling problematic situations.

In some of the groups I followed in the end of the 1980s, several of these preconditions were present. The workers helped a small number of care recipients and had a thorough knowledge about their needs, habits and wants. The time allocated for each care session was reasonably generous and the care workers and care recipients could decide together what to do today and what to do next time. Thus, there was enough continuity, time and discretion. However, support from supervisors or managers was more or less absent in all the groups. The workers were mainly left alone to handle many difficult situations.

Since the time I conducted the empirical work for my thesis, a number of socio-political and organisational changes have taken place – most of them in the wrong direction. A quick look back at the history of home care reveals some of these “de-caring” organisational trends.

Up until the early 1950s, older people in need of care in Sweden and in most other countries, were almost entirely confined to institutions like old-age homes (or they were left to the support of their children, mainly the daughters – irrespective whether their relationship was good or bad). So when home care services started to develop on a small scale, inspired by the British experience during the Second World War, it was actually a “freedom of choice revolution” – long before the more recent use of the word in the trend of marketisation. For the first time, frail older people could choose to stay in their own homes and receive help from paid care workers. They didn’t have to depend on their children and they didn’t have to move to an old-age home when they no longer could manage without help at home.

In Sweden, the home care services grew very rapidly – from 60,000 persons in 1960 to 250,000 individuals in 1980 – more than 4 times as many in 20 years, and faster growth than childcare a decade or two later. Both forms of care are important parts of *social infrastructure* in the Nordic welfare state. Both childcare and eldercare are welfare services that have made it possible for both women and men in all social groups to be gainfully employed even in situations when there are family members needing care.

In practice, the growth of home care services made it possible for women to be *working daughters* – just like childcare made it possible for women and men to be *working mothers and fathers*. Therefore, I have argued for many years that politicians have to stop thinking about eldercare as just a cost – if we don’t have well-functioning eldercare services, middle-aged women (and men) cannot work or at least not focus on their jobs. And when we are getting older, if we know that there are good services available, we don’t have to worry whether we will get the care we need today or tomorrow.

It has been argued that the expansion of home care services in the 1960s and 70s was important in changing the general view of the welfare state. Home care was the first welfare service with universal ambitions that large number of people had a personal experience of – and were happy with! This was in contrast to old-age homes that were part of the poor law system. Unlike old-age homes, home care became popular among all social groups and has been used by both rich and poor. Home care was an important, but unacknowledged, part of the growing welfare state.

So how come that home care became so popular and the first truly universal welfare service? I would say that it is because the services were *accessible* for all and *affordable* also for the poor (supported by generous state subsidies) and they were *attractive* also for the middle class. Without the combination of accessibility, affordability and attractiveness, a welfare service would never had become universal – used by all social groups. Services have to be there when you need them, you have to be able to afford them, and you have to be satisfied with the offer.

To be attractive, services have to be individually adapted. Some people believe that there is a conflict between universalism and individually adapted services. I disagree. I would say that it is the opposite. If publicly funded services are not adapted to the individuals who use them, those who can afford it will buy private services instead. The architects of the Swedish model – “the people homes” (folkhemmet) – knew that, when they argued that “only the best is good enough for the people”. The argument was that only if all social groups use the same service will those with few resources also get good services. This is in line with the British social policy analyst Richard Titmuss’ argument that “services for poor people have always tended to be poor quality services”.

So the development of home care services in the 1950s, 60s and 70s was part of the growth of the welfare state. Home care was an accessible, affordable and attractive service. It was attractive because the way the service was organised left the worker with enough time and discretion to adapt the help to the varying situations of a limited number of care recipients. However, the work itself was not regarded as a proper job. In the beginning, housewives were employed by the hour, the pay was lower than in, for instance, cleaning jobs and no formal training was required. Informal qualifications, such as the care workers’ experience of home-making and informal care, that were necessary for coping with the work, were not recognised.

From the second half of the 1980s, rationalisation strategies aiming at cost efficiency were introduced. A Taylorisation of care work took place: the daily organisation of home care became increasingly pre-determined; the tasks to be carried out at each occasion were set in advance; and a horizontal and vertical division of labour along with a standardisation and fragmentation of care into manageable ‘care products’ were introduced.

More recently, these 'de-caring' organisational trends have increased with the international wave of market-inspired reforms often labelled 'New Public Management' (NPM). A central aspect of NPM is the introduction of a purchaser-provider split: a division between the purchaser/needs assessor and provider units, which led to significant change in the daily organisation of home-care services. It increased the distance between the 'office' and the 'workshop'; between the decisions and the actual provision of help. This resulted in new demands for exactness and clarity in the 'order', such that increasingly often work tasks are connected to a standardised time frame that allocates, for example, 5 minutes to make a bed, 10 minutes to change incontinence pads or 15 minutes for a shower.

When private care companies entered the field, services became increasingly pre-regulated and new instruments were developed to measure the quality of care and to ensure that the tasks performed accorded with the needs assessment. Care workers perceive this detailed, pre-regulated organisation of their daily work as stopwatch tyranny – a system in many ways similar to the assembly line in factories introduced more than a century ago by Frederick Winslow Taylor who turned the stopwatch into the symbol of industrial tyranny.

These organisational changes have been introduced along with cutbacks to the services. Public funding has not kept pace with the ageing population since 1990. First the number of home care recipients started to decline but particularly over the last two decades we have seen a drastic reduction of care home places. In the year 2000, 20 percent of people aged 80 years or more lived in a care home (nursing homes, residential care). Just twenty years later, the proportion is 11 percent. The coverage of home care has not compensated for the decline – a more or less unchanged proportion of the population 80 years and older received home care in 2000 and in 2020 (around 20 percent) – down from one third of the older population in the heyday of home care in 1980. One of the consequences of the raised threshold for accessing a care home is that both care home residents and home care users have increasingly large care needs. Unfortunately, staffing levels have not increased to meet the increasing needs.

In my research group, we initiated a survey of care workers in 2005 and followed up with a similar study in 2015. In the 1980s, the number of clients a home care worker helped during an ordinary work day was 4 or 5. The survey showed that this number had increased to 9 in

2005 and to 12 per day in 2015, seen over an average of 15 visits per day, of which half were 15 minutes or shorter.

Recent statistics from Swedish authorities show that, today, over a two week period each home care recipient receives help from an average of 15 care workers. Thus, the continuity of care is significantly reduced.

Our survey also showed that the home care work has become increasingly time-squeezed and the scope for support from colleagues and managers has been reduced. The most striking difference between 2005 and 2015 is that the home care workers reported much less autonomy in their job: their opportunities to affect their daily work had significantly reduced. So all four important preconditions for good care – and good work – time, continuity, discretion and support had deteriorated over the decade. Obviously, new organisational models have been introduced in stark opposition to the actual results of care research.

Despite these de-caring organisational trends, ageing-in-place policies are increasingly popular among national and local politicians. Older people with increasing care needs are supposed to stay in their homes as long as possible. A number of studies in Sweden suggest that, even if the politicians believe that intensive home care is cost-saving and more popular than care homes among those in need of care, this idea is less attractive for older people with large care needs themselves. Already when I interviewed home care recipients for my thesis in the late 1980s, they told me that they were worried that they would not get access to a care home when they needed more care. Thirty years later, our research group conducted a survey of middle-aged women and men asking about their experiences of care of family members. Here the limits of ageing-in-place policies became increasingly clear! A quote from a middle-aged daughter who responded the survey serves to illustrate family members' worries about home care and also the relief this daughter felt once the struggle to get a place in a care home for her mother had been successful:

“Home-care staff that came 6–7 times per day was chaotic! The home no longer felt like a safe place. New people came and went: 50–60 different persons in a three-month period. Constantly new staff that walk around in your home.... Living at home sounds good but is not a solution for everyone. It got better in the care home. It is

safe as there are always staff nearby. Nice to sit and eat together with others. When the staff are the same, it is also safe for the family.”

A bit paradoxically, care homes have become more attractive while home care has become less so. But in both arenas of care, the working conditions of the care workers have deteriorated. For the workers in care homes, the workload has increased, they more often work understaffed and they leave the job more physically and mentally exhausted after the workday, and they increasingly have to go home with a feeling that they have not been able to meet the needs of the residents they are helping. Not surprisingly, half of the workers in our 2015 survey reported that they seriously had considered quitting their job – up from 40 per cent ten years earlier.

Compared to the birth of home care services in the 1950s, certainly many things have become better. Today the majority of care workers have formal training, but it is still possible start working in the care sector without any training. The pay is still low and a large proportion (around one quarter of the workforce) are still employed by the hour. Care workers are still taking care of other people’s health needs at the expense of their own health. Institutional recognition of care work is still weak, reflecting the pervasive, gendered undervaluation of care.

I don’t have time to talk about all the exciting studies my colleagues are doing right now in care homes and in home care; studies focusing on care recipients, their families, care workers and their managers. Instead I want to end with a couple of words on COVID-19 and the changes the pandemic might lead to. A number of authorities have recently drawn the same conclusion that we care researchers have been stressing for many years.

For instance, the World Health Organisation noticed last summer:

“The COVID-19 pandemic has (...) highlighted long-standing problems in the long-term care systems in most countries: underfunding, lack of accountability, fragmentation, poor coordination between health and long-term care, and an undervalued workforce.”

For the moment, politicians in many countries, including Sweden, are promising to increase resources to the care sector and to improve the quality of care. I really hope that they will not forget these promises when the media’s searchlight has turned to another problem. And

I also really hope that they will listen to the people who are living the daily life of care: care recipients, their families and care workers! And to care researchers!

I hope for more resources for eldercare, for more formal training for the staff – and preconditions to use the training. I hope for more time, more support from managers and health care professionals and better employment conditions. I hope for a way of organising care work that allows workers and care users to get to know each other and an organisation that allows enough autonomy for care workers so they can adapt to the changing situation of each care user. I hope for a way of organising care work that leaves both users and workers satisfied.

Care services are an essential part of the equality ambitions of the Nordic model. These services are often regarded as the embodiment of the women-friendliness of Nordic welfare states. There is no doubt that eldercare – both home care and care homes – has been empowering for many women as care users and family members of older persons in need of care. This is somewhat less the case after the cut-backs and ‘de-caring’ organisational trends, but still we have very many well-functioning services – both home care and care homes! Our eldercare services are definitely well worth defending as an important part of a welfare system with universal ambitions. However, care workers have, in practice, not been included in the equality ambitions of the Nordic welfare states and the welfare state has never been particularly women-friendly for them. It has not been a good employer. To achieve improvements in eldercare services, this must be changed.

Once again, I wish to express my deepest gratitude to the Nordic Gerontological Federation that has chosen to award me the Sohlberg Prize and given me this opportunity to talk on a topic that is so close to my heart – a topic that gets even closer as I soon will reach the age when I will need care myself. Therefore – but also for the sake of present and future care recipients, their families and care workers: I wish the best of luck to all gerontologists and care researchers – continue your important work!